

How and how well have older people been engaged in health care intervention design, development or delivery using co-methodologies: a scoping review with narrative summary

Abstract

Co-methodological working is gaining increasing traction in health care, but studies with older people have been slower to develop. Our aim was to investigate *how* and *how well* older people have been engaged in health care intervention design, development or delivery using co-methodologies. We conducted a systematic search of four electronic databases to identify international literature published between 2009 and November 2019. We included peer-reviewed empirical research of any design. Three authors screened papers. Our review is reported in accordance with the Joanna Briggs Institute manual for scoping reviews, we have referred to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement. We data extracted to a bespoke spreadsheet and used the Co:Create Co-production Matrix to guide quality appraisal. Included studies (n=48) were diverse in nature of interventions, co-methodologies and reporting. We offer a narrative summary of included papers. Establishing *how* older people were engaged in co-methodological work was largely straightforward. *How well* this was done was more challenging, however we have identified gems of good practice and offered directions for future practice. The Co:Create Co-Production Matrix was the best fit for evaluating papers, however it is not intended as a measure per se. In essence we argue that notions of 'best' and 'scores' are an oxymoron in co-methodological working, what is important that: i) researchers embrace these methods, ii) incremental change is the way forward, iii) researchers need to do what is right for people and purpose and iv) have time to consider and articulate *why* they are choosing this approach and how best this can be achieved for their particular situation. Future evaluation of participant's experience of the process would enable others to learn about what works for who and in what circumstances.

What is known about this topic?

- Co-methodological working has become increasingly valued in health care
- It is used less with older people

What this paper adds

- Co-methods frameworks, of which there are many, imply achievement of each included element is necessary.
- Engagement at every stage of a project may be unrealistic if studies are prolonged and the level of commitment beyond what any older person can offer.
- Reporting *what* co-methods work, *when* and for *whom*, would enhance future co-methodological research and practice.

KEYWORDS: older, co-method, co-design, co-production, co-creation, participatory, review, health, intervention

Introduction

Co-methodologies in health care are increasingly considered to be a “good thing”. However, the language of “co” working is not fully defined and remains a fundamentally contested concept (Flinders, Wood & Cunningham, 2016). The terms co-design, co-production, co-creation, participatory research or participatory design are increasingly used, sometimes interchangeably by researchers and research funders (National Institute for Health Research (NIHR) INVOLVE, 2020). For some, co-methods are synonymous with Patient and Public Involvement and Engagement (PPIE), whilst for others they represent a much more considered approach in which lay people and professionals work as equals at every stage in the research process (NIHR, 2020, Co:Create, 2020).

Over the years, efforts have been made to devise methods of assessing forms of participation, some models express these hierarchically based on different criteria. The most frequently cited are the ladder of participation (Arnstein, 1969) and the typology of participation (Pretty, 1995). Whilst a good starting point, these tools have been widely critiqued. Some argue that Arnstein (1969) over-emphasises power and, the lack of acknowledgement of different forms of knowledge and expertise limit the value of the typology (Tritter & McCallum, 2006). Cornwall (2008) states that both models retain a certain vagueness about the meaning of participation and suggest more attention needs to be paid to *“who is participating, in what and for whose benefit”*. Some authors suggest non-linear approaches such as the Capire Engagement Triangle (CAPIRE, 2020) and the Spinning Wheel of Participation (Davidson, 1998). The Capire Engagement Triangle identifies desired outcomes of engagement based on the overarching objectives of informing decisions, building capacity and strengthening relationships. The non-linear nature of the tool means that it describes meeting these different objectives, however, it also assumes that participants need to be ‘educated’ and have their knowledge ‘increased’ or behaviour ‘changed’ (specified in the objective of building capacity). The tool does not include ‘empowerment’ and/or acquiring an ‘equal partnership’, as one of its objectives, thus like other models, the Engagement Triangle tool also appears to take a ‘top-down’

and a 'tokenistic' approach. The 'Spinning Wheel of Participation' is intended to define and encourage levels of citizen participation for community planning (Davidson, 1998). The spinning wheel is made up of four key themes, information, consultation, participation and empowerment and requires considerable commitment from community members. Aner (2016) outlines four increments of participation level when engaging with older people; *i) 'right to be informed, ii) right to be heard, iii) right to codetermine and iv) right to self-organization'*. This paper spans participation from three perspectives; older people's own interests, policy and legislation, and research and practice. The authors identify essential elements of effective participation including working together and creating opportunities to be engaged at different stages of research. Teoh, Tan, Tan and Chong (2018) report two key challenges in co-methods work, firstly the potential for hierarchy within the team and secondly power dynamics.

In seminal work, Reed (2008) offered eight points of best practice in stakeholder participation. A decade later, Reed, *et al.* (2018) categorised stakeholder and public engagement in the Wheel of Participation as: *i) top-down one-way communication and/or consultation, ii) top-down deliberation, and/or co-production, iii) bottom-up one-way communication and/or consultation and iv) bottom-up deliberation, and/or co-production*. These authors suggest that the approach taken explains variation of outcomes. Hurlbert & Gupta (2015) offer a split ladder of participation which they describe as a diagnostic, evaluation and strategic tool. Both Reed, *et al.* (2018) and Hurlbert & Gupta (2015) offer methodologically robust approaches, however their work is complex to apply in real world settings.

The value and challenge of achieving 'good' co-working is well rehearsed in the literature (Ramirez, 2020). Advice on co-working is becoming increasingly available, for example 'Co:Create' offer a Co-production Matrix for self-evaluation purposes (Co:Create 2020) and Ramirez (2020) a 'meditation' on meaningful participation. Good practice guidance is summarised in several documents (Flinders,

et al. 2016; NIHR, 2020; Shimmin, Wittmeier, Lavoie, Wicklund & Sibley, 2017). Synthesis of these varied sources suggests common themes that contribute to 'good' co-working which include: engaging all stakeholders from an early stage, valuing the perspectives of all participants, avoiding existing stereotypes and managing power relations and inter-personal interactions.

Further value of using co-methods in health care research include bringing together researchers, healthcare staff and end users earlier in the research process, facilitating genuine innovation and improving performance (Jackson & Greenhalgh, 2015). This approach is congruent with current policy, particularly regarding the increasing emphasis on pragmatic, 'real world' approaches where, for complex interventions to be effective, they must be adapted to local contexts (Jackson & Greenhalgh, 2015). Increasing recognition of this value provides the opportunity to explore the extent to which different studies have achieved co-methodological working.

With a worldwide ageing population (World Health Organisation (WHO) 2020a), research must better address the needs of older people. In this paper we focus on *how* and *how well* older people have been engaged in health care intervention design, development or delivery using co-methodologies. For the purpose of the paper we have defined older as participants described by authors as older, elder or senior. However, we acknowledge that definitions of older persons vary widely. Most developed countries use the chronological age of 65 years as a definition of 'elderly' or older person (World Health Organisation (WHO) 2020b). This age is also an implicit marker of old age by the United Nations (2020). Perceptions of old age are influenced by culture and also the age of the person offering the definition. For example, people in early adulthood tend to categorise any age from 50 years upwards as old (Aged Care Guide, 2020). Globally there is a steady rise in the number of centenarians (Robine & Cubaynes, 2017) and many people may experience living in older age over a long time span during which their health and wellbeing will inevitably change.

Research partnerships with older people are increasing, but the ethos of co-methods have been slower to develop with this group than with others (Blair & Minkler, 2009; Littlechild, Tanner & Hall, 2015) and older people are at risk of systemic exclusion (Shimmin, et al. 2017). Ability and desire to engage in co-methodological working will vary between individuals but may also be influenced by age; for example the 'older old', those aged over 80 years are more likely to be living with sensory and cognitive impairment (Wayne & Johnsrude 2015). As the silent generation, they may need more support to express their views and needs (McIntosh-Elkins, McRitchie & Scoones, 2007).

At present there is a dearth of literature that fully illuminates process, practice and benefits of co-methodological working with older people in healthcare. Given the current trend towards co-methodological working and the relative lack of guidance on approaches with older people (Littlechild, et al. 2015), this review aims to investigate *how* and *how well* older people have been engaged in health care intervention design, development or delivery using co-methodologies. We have chosen to focus on a wide breadth of healthcare including interventions in primary care, secondary care and the community setting, however to provide a degree of focus we excluded non-direct health interventions, for example public health interventions such as those addressing the environment, housing or social isolation. Mapping, synthesis and identification of gems of good practice in available literature will be of value for clinicians, managers and policy makers who are planning such endeavours. This new knowledge will help to inform future co-working and benefit the older population.

For clarity, we have used co-methods (C-M) / co-methodological working (C-MW) as umbrella terms, but have referred to specific approaches as reported in each included paper. The protocol for this review is registered at the Centre for Open Science, Open Science Framework (Cowdell, Dyson, Sykes, Dam & Pendleton, 2020)

Objectives

To conduct a scoping review of empirical research reporting use of co-methodological working with older people in relation to design, development or delivery of healthcare interventions. The review questions were:

1. *How* have older people been engaged in co-methodological working in relation to healthcare interventions?
2. *How well* have older people been engaged in co-methodological working in relation to healthcare interventions?

Methods

Design

Our review is reported in accordance with the Joanna Briggs Institute (JBI) manual for scoping reviews, as our aim was to provide a broad overview of our topic (Peters, et al. 2020). For completeness we have referred to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff & Altman, 2009). How well older people have been engaged in C-MW is considered in relation to the Co:Create Coproduction Matrix. We offer a narrative summary of included papers and identify gems of good practice, by which we mean small extracts to which we were drawn and which offered a key to understanding what matters in C-MW with older people and which illuminate researcher's commitment to C-MW and may inform future planning.

Study selection

We conducted a systematic search of the electronic databases The Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, PsycINFO and Applied Social Sciences Index and Abstracts (ASSIA). Databases were selected to capture key health literature. A limit of ten years was

applied (2009 - November 2019) as C-MW is a rapidly evolving field. To aid the development of key search terms (see Table 1) we used the PICO (Population, Intervention and Context) framework (Moule, Aveyard & Goodman 2014). Boolean terms including truncation were applied but MeSH terms were not used to avoid inadvertent exclusions. Additionally we searched for existing reviews in Prospero and the Cochrane Database of Systematic Reviews. We completed forward and backward citation searching of included papers. We did not engage with the grey literature as our focus was solely on peer reviewed work.

Inset Table 1 here (Table 1 Key search terms)

Study eligibility

Inclusion criteria included international peer-reviewed empirical research studies published in English language. We were interested in health related C-MW with older people. Further details of eligibility are summarised in Table 2.

Inset Table 2 here (Table 2 Eligibility Criteria)

Search outcomes

We examined a total of 2093 titles with 1886 being excluded as not relevant to the aim of our review. Subsequently two authors (JD, FC) independently reviewed the remaining 207 full texts. Of these 159 were excluded. We resolved disagreements by discussion and when required by consulting with a third author (MS). Reasons for exclusion were; no evidence of C-MW, not older person specific and descriptive papers. No literature reviews of any type were identified. Forty eight papers are included in our review. Figure 1 outlines the process of study selection.

Inset Figure 1 here (Figure 1: PRISMA diagram of study selection process)

Quality appraisal

Our review focused on quality of C-MW rather than quality of the research per se. For this reason we did not assess methodological quality as this may have excluded papers that included information pertinent to our review. As discussed above, we assessed quality of C-MW against the Co-create Matrix. We are mindful that the Matrix is intended as a self-assessment tool rather than as a quality measure for papers reporting C-M studies, nevertheless it offers a framework that we consider most congruent with current thinking about C-M, particularly in the context of healthcare. The eight Co:Create descriptors can be assessed at “we’re not doing this and we’ve not started to think about it yet” which we scored at zero, Bronze (score 1), Silver (score 2) and Gold (score 3). The minimum score possible was zero and maximum 24. These descriptors are the closest fit with our area of interest and are presented in Table 3. Quality appraisal was conducted separately by two authors (FC, RP) with any discrepancies being resolved in discussion with a third author (JD). Where appropriate we extracted gems.

Insert Table 3 here (Table 3 Co:Create Co-production Matrix)

Data extraction

The papers (n=48) were divided between authors and each extracted data independently. We then discussed a sample of papers (n=18) selected arbitrarily, and any discrepancies were identified and resolved as a team. Adjustments to data extraction from other papers was made if required to ensure consistency. To address our review question, we designed a bespoke data extraction sheet with a focus on extracting data directly relevant to co-methodological working with older people. Specifically we wanted to i) map the type of interventions being co-created (aim of study) ii) identify focus of the paper, whether reporting on the intervention development per se or offering a process evaluation (methodology), iii) report details regarding C-MW (co-approach, aim of co-approach, summary of co-procedures) and iv) provide a total Co:Create score. Data extraction is summarised in Table 4.

Insert Table 4 here (Table 4 Data extraction from included papers)

Data synthesis

The included papers (n=48) were heterogeneous in nature with a mix of qualitative and mixed methodologies and process evaluations reporting C-MW from differing perspectives. All papers reported on C-M to a greater or lesser degree. We conducted a narrative synthesis through textual description to identify commonalities and gems to progress understanding of how best to engage older people in C-MW. Through this we offer coherence in a diverse body of evidence (Campbell, Katikireddi, Sowden, McKenzie & Thomson, 2018). In presenting our results we firstly offer a summary of study characteristics. We then focus on our review objectives to assess of *how* and *how well* older people have been engaged in C-MW. Finally, we synthesise learning from reported studies and point towards future research and practice possibilities.

Results

Study characteristics

The majority of studies were conducted in the UK (n=13) and the USA (n=12). Other countries included the Netherlands and Canada (n=5 each), Australia and Sweden (n=3 each), one each from Slovenia, Denmark, Thailand, Ireland and China. Two papers report on dual country studies involving Netherlands/Hungary (n=1) and Netherlands/Italy (n=1). In many cases it was not clear in what type of venue the work was conducted, but most were sited within local communities. Methodologically we have categorised papers as broadly qualitative (n=32), mixed methods (n=3) or process evaluation (n= 13) according to the major focus of the paper. In reality, this represents a continuum as many authors report on a combination of primary research with a greater or lesser degree of reflection on C-MW. External funding is reported in most papers (n=37), this ranges from modest scholarships to large national grants.

Interventions reported ranged from equipment design, for example mobility aids (Boerema, van Velsen, Vollenbroek-Hutten & Hermens, 2016) and bottle openability (Flinn, Sanders, Yen, Sommerich & Lavender, 2013), production of culturally appropriate information for patients (e.g. Parker, et al. 2012), development of on-line resources, for example telemedicine and telehealth solutions (Duh, Guna, Pogačnik & Sodnik, 2016) and an eHealth carer needs assessment tool (Giroux, et al. 2019). Whilst some projects had a micro focus, for example Baur & Abma (2012) worked to improve meals in one residential home, others undertook work to intended to have a wider sphere of influence through health promotion interventions (e.g. Bone, et al. 2013; Schensul, Radda, Coman & Vazquez, 2009).

Types of participant varied across studies with 15 involving only researchers and older people. Detail about the constitution and expertise of the research teams in these studies is sparse but some are clearly multi-disciplinary, for example Sandlund, et al. (2016) includes researchers with expertise in physiotherapy, informatics and knowledge engineering. The remainder of the studies (n= 33) engaged broader teams including informal caregivers, members of the wider community, influential stakeholders (e.g. elder services providers, advocates, senior housing managers), subject experts (e.g. educators, sociologists, nutritional scientists, graphic or industrial designers, software engineers), clinical experts (e.g. nurses, medical staff, physiotherapists). Nguyen, *et al.* (2018) and Span, *et al.* (2018) engaged with different combinations of participants for each stage of the process. Where reported, older person participant numbers ranged from seven (Baur & Abma, 2012) to 386 (James, Blomberg, Liljekvist & Kihlgren, 2015). The age of older participants is detailed in some studies, but many offer general terms such as 'older adults', 'older people' or 'mid-life or older members'. Where specified participants were aged 55 years or older.

Methodological quality

The assessment details of co-methodological quality for each of the included studies are presented in Supplementary File 1 with an overall score offered in Table 4. No studies scored zero "we're not

doing this and we've not started to think about it yet" for any descriptor, as all had at least implicitly considered every descriptor at some level. Figure 2 presents a summary of scores across papers by descriptor. We expected that process evaluation papers would achieve higher scores in view of the focus, but this was not the case. Scores ranged from 8 in a mixed-methods paper by Smith-Jackson, Kim, Suh & Ryu (2010) to 21 in a qualitative report by Schensul, *et al.* (2009). The descriptors with the lowest scores overall were for 'resourced' with papers scoring 1 (bronze) (n=23) and 'sustainable' scoring 1 (n=24). Scores of 3 (gold) were most frequent for the descriptors 'inclusive' (n=11) and 'iterative' (=10). We treat total scores with caution, as many papers report on high quality co-methodological working in discrete areas, for example in intervention design. This perhaps reflects the relative immaturity and specific challenges of C-MW with older people with or without associated health conditions.

Insert Figure 2 here (Figure 2 Summary of quality appraisal scores across papers by descriptor)

Findings

How were older people engaged in co-methodological working?

Precise description and underpinning theory of the C-M used is absent in many papers. Broadly methods comprised participatory +/- action research (n=22), co-methods (including co-design, co-creation and co-research) (n=14), Community Based Participatory Research (n=6) and one each of Priority Setting Partnership, World Café, Method for Planned Adaptation through community engagement, multi-level peer-led empowerment intervention, practical participatory evaluation and co-operative inquiry. Authors generally provided underpinning theory of C-MW in background sections, but explanation of practical application in the project is reported infrequently.

Our data extraction included the specific aim of the C-MW. In many cases this was presented as a variation to the aim of the study itself or in vague language for example, to work in a participatory and responsive manner (Clarke, Sanders, Seymour, Gott & Welton, 2009). Others were more precise,

for example to engage wheel chair users, care providers and clinicians in an iterative design and development process (Giesbrecht, Miller, Mitchell & Woodgate, 2014).

The most frequently reported type of engagement was through variously described communication such as interviews, focus groups, facilitated discussions, community consultation and workshops. Some older people worked practically alongside researchers to design and/or test 'products' for example a re-ablement system (Bond, Mulvenna, Finlay & Martin, 2015), a peer-education guide (Clarke, et al. 2009), development of a home based dizziness intervention (Grönvall & Kyng, 2013) and a digital life-story book (Subramaniam & Woods, 2016).

How well were older people engaged in co-methodological working?

We report here according to descriptors of the Co:Creation Matrix. In each case a brief overview of the descriptor is provided as the context for our assessment.

Holistic: Best practice guidance suggests that C-MW should take place at every stage of a project including planning, delivery, evaluation and governance. In virtually every included paper the original study idea was generated before the C-M team was constituted. To some extent this is inevitable in that i) until researchers know the question they are addressing they are not able to seek the older people with the required knowledge and experience and ii) all research activity has to be resourced and until funding is secured it is not always possible to progress. Although many funders now require PPIE in applications, this is often quite separate from the research that follows. In the United Kingdom (UK) there is a move towards C-MW to identify important research questions for specific conditions through priority setting partnerships (PSP) (James Lind Alliance, 2020).

Early stage older person engagement is evident in a PSP to prioritise the research agenda in improving the oral health of older people (Brocklehurst, Mackay, Goldthorpe & Pretty, 2015). However this PSP followed the prescribed design and although older people were involved at each

stage up to question generation it is not clear what part, if any, they played in disseminating the work and influencing research to address prioritised questions. Two studies engaged older people at the design stage, to improve cancer screening (Bone, et al. 2013) and to develop a culturally appropriate diabetes intervention (Wang-Letzkus, Washington, Calvillo & Anderson, 2012). Other studies report C-MW at multiple stages including for example, design workshops and committee meetings (Tremblay, et al. 2019), group meeting with site meetings and intervention refinement processes (van Velsen, et al. 2015) and designing interview tools, participant recruitment, interviewing, data analysis and dissemination of findings (Ellins & Glasby, 2016). The most comprehensively reported element in most papers is the 'doing' element of C-MW through communication and design and/or testing of 'products' as discussed above. Few studies explicitly report co-data analysis, in most instances there is a sense that researchers 'take' the data, analyse it and, in some cases, present it back to the group. Dissemination activity appears to occur post project in most studies. Study governance is not explicitly addressed in any included paper.

Resourced: Excellent C-MW requires sufficient resource. Although financial support is crucial, perhaps more important is the need for adequate time for the project and the ability to adjust timescales and process as the project progresses to ensure that C-MW is achieved. The majority of studies report external funding, but the value of this to C-MW per se is not specified.

Reimbursement for participation is recorded by Giroux, *et al.* (2019) and adjustments to timescales by Ralston, Young-Clark & Coccia (2017) and Revenäs, *et al.* (2018). Only three studies explicitly report resource in terms of extra time being used to adapt to enable full engagement of a 'weak group' (Grönvall & Kyng, 2013), people with dementia (Revenäs, et al. 2018) and the whole team (Ellins & Glasby, 2016). Researchers invested time and thought into project planning prior to older person engagement, however reports suggest that the C-MW was delivered at a pre-ordained time and using methods fixed by the researchers in advance, but this does not imply that the C-MW was without benefit.

Transparent: Older people should understand why they are involved in C-MW, their remit in the project and should be able to reframe the work as it progresses. Reporting of older people's understanding of their role suggested that in most cases they understood the purpose of the research rather than appreciating the purpose of CM-W in and of itself. This is perhaps reflective of some uncertainty for the research team about why they were using C-Ms. Other than that it is a 'good thing', few papers clearly articulated the aims and added value of this approach.

Detail about how older people were prepared for C-MW or their understanding of overall aims, limitations, expectations and commitment is not often reported. Exceptions are Baur & Abma (2012) who conducted an early stage informational dialogue group with older residents who, having had time to think, were able to opt into C-MW. Preparation for C-MW was provided by Ellins & Glasby (2016) in a series of five training sessions. Other teams offered training for specific elements, for example training on interview techniques (Jacobs, 2010), focus groups in preparation for the participatory design session (Lucero, et al. 2014), three sessions to prepare co-researchers (Tanner, 2012) and a training session on photo-voice (Yankeelov, Faul, D'Ambrosio, Collins & Gordon, 2015). In reality, it is likely that many older participants received a research participant information sheet, as required by most research ethics committees, and this is simply not reported. It does however suggest that the C-MW approach is well established before the older people join the team.

Inclusive: C-MW is intended to engage all members, with activities being designed to be accessible and a range of viewpoints represented. In some cases, for example (Allen, et al. 2016; Baur & Abma, 2012; Flinn, et al. 2013) there is marked demographic homogeneity in older persons thus limiting the opportunities for including wide ranging views. Likewise, in a minority of cases, the 'usual suspects' have been engaged through existing channels such as the Alzheimer's Society research network volunteers (Rapaport, et al., 2018) limiting diversity and breadth of understandings and experience. Several studies report multi-disciplinary, lay-professional-practitioner-researcher C-MW, for example

Bond *et al.* (2015) included alongside older people and researchers, developers, direct users and industry re-ablement representatives. Similarly service users, third sector partners and professionals worked together on a PSP (Brocklehurst, et al. 2015). In some cases, entirely appropriately, projects included only small numbers of older people and researchers or older people from specific groups. For example, Tanner (2012) worked intensively with three older persons with dementia to prepare and support them in interviewing peers. Likewise, Grönvall & Kyng (2013) worked in triads with older persons in their own home and a specialist physiotherapist to maximise opportunity for the design and development of a home-based, technology assisted, dizziness prevention intervention that would be acceptable for, and used by, older people. The aim for cultural competence guided the recruitment of older persons in creating a talking book for Vietnamese elders with dementia (Goeman, et al. 2016) and in exploring palliative and hospice care with Native Americans (Isaacson, 2018). Inclusivity is clearly concerned with getting the right people for the study, rather than aiming for large numbers or unwarranted diversity.

Iterative: Ideally C-MW should be a reciprocal and progressive endeavour in which each stage informs the next; feedback loops engaging all participants are critical to success. Few studies started with a blank canvas and as expected, all were grounded in knowledge from current literature and previous work of the research team. Many built on some form of existing entity, for example, Goeman, *et al.* (2016) adapted information to develop a culturally appropriate ‘talking book’ for the older Vietnamese community, Hales & Fossey (2018) built on current Cognitive Behaviour Therapy (CBT) interventions to design a package specifically for the carers of people with dementia and Jewitt, *et al.* (2016) to improve and evaluate current patient information on lung radiotherapy. Feedback is an area of strength in most papers and all reported some related activity. Two types of feedback predominated i) older person evaluation of ‘products’ for example a prototype web-based falls prevention system (Lucero, et al., 2014) and ii) researcher led feedback from one session used to introduce the next. Papers we assessed at the highest level went beyond feedback alone to report

how group responses were integrated into the next stage of the project; for example changing direction of the project (Baur & Abma, 2012), amending plans (Clarke, et al. 2009) and reconsidering interventions (Ellins & Glasby, 2016; Wang-Letzkus, et al. 2012).

Positive: All members should be valued, heard, engaged, committed and empowered. Building relationships is key to positive C-MW experiences but reporting is limited. Exceptions include, for example, one instance of emphasis on getting to know each other and feeling more comfortable in order to share experiences (Baur & Abma, 2012), two reports of development and maintenance of relationships across the team (Span, et al. 2018; Tanner, 2012) and one description of using the culturally sensitive ‘talking circle’ method to promote communication (Isaacson, 2018). Details of how older persons’ views were elicited are well documented. However, in many instances there was a sense of views being ‘taken’ by researchers and used to progress the project with limited input from older participants. Nuanced evaluation from older people about their experiences of C-MW was notably absent, indeed many authors did not reflect on this at all. Some suggested that feedback was broadly positive (Brocklehurst, et al. 2015; Bulsara, Khong, Hill & Hill, 2016; Clarke, et al. 2009; Tanner, 2012). Bone, *et al.* (2013) imply that older people were able to articulate the specific value of C-MW in creating a new navigation system. Older participants designing a Parkinson’s disease eHealth intervention suggested how future C-MW may be enhanced (Revenäs, et al. 2018) and in the case of Schensul, *et al.* (2009) they envisaged ongoing engagement beyond the life of the project.

Equal: All C-M participants should be equal, power imbalances should be addressed and solutions to problems should be address collaboratively. Around two thirds of included studies were researcher led and five did not explicitly state leadership (Boerema, et al. 2016; Clarke, et al. 2009; Holliday, Ward, Fielden & Williams, 2015; Morrison & Dearden, 2013; Wang-Letzkus, et al. 2012). Exceptions included studies that claimed to be ‘stakeholder-led’ (Bond, et al. 2015) or guided and advised by a

committee or project team (Bone, et al. 2013; James, et al, 2015; Nguyen, *et al.* 2019; Ralston, et al. 2017). Three teams adopted a model of shared control (Hwang, et al. 2015; Sukwatjane, et al. 2011; Wang, et al. 2014). There was one example of participants leading the agenda and priorities although the overall project was led by researchers (Yankeelov, et al. 2015). There are different forms of leadership, and democratic approaches with equal weight given to opinions of older people may be most apposite. The greatest need is to ensure that older person contributions are explicitly valued and form part of the project as a whole. Equality is not necessarily desirable or achievable and it may be that equity is a more realistic aim. There is a need to consider power within the team; this is only explicitly addressed in three papers. Morrison & Dearden (2013) report actively avoiding power differentials through the use of mechanisms such as shared language and engagement with artefacts. Dominant and silent participants were managed using skilful facilitation by Revenäs, *et al.* (2018) and this approach was used by Zeitz, *et al.* (2011) to mitigate tensions between clinicians and older people when the latter thought that they were merely being used to 'rubber-stamp' existing decisions.

Sustainable: Impact of CM-W on sustainability of the project should be clear to all and evidenced, with older people able to articulate the value of the endeavour. In general papers reported one-off C-M projects. Whilst many papers suggest good project outcomes, for example the availability of a new website, patient information leaflet or aid, few document experiences of older participants or indicate if or how the group may work together in the future and how the outputs from the project will be initiated and sustained. There are exceptions with older people reporting 'very rewarding' (Allen, et al. 2015) and 'empowering' and 'positive' experiences (Bulsara, et al. 2015). Carers and professional participants reported co-researchers with dementia had enjoyed the process of interviewing and suggested it had increased their self-esteem and social skills (Tanner, 2012). Older people engaged in a World Café expressed a desire for their falls prevention work to continue (Bulsara, et al. 2016). Similarly, older people designing a Parkinson's eHealth intervention envisaged

possibilities for further co-design (Revenäs, et al. 2018). In two cases co-working groups stayed together beyond the life of the project. Both were community focused, Clarke *et al.* (2009) developed peer education and Schensul, et al. (2009) a programme to increase uptake of influenza vaccinations. It is possible that in these instances the older people felt more in control and at ease with their role as they were working in their own communities.

Intention of future C-MW is implied by authors who reflect on lessons learnt from the C-M project. However, discussion is often superficial and largely based on the opinions of authors rather than data, and focuses on outputs rather than C-MW processes. Three key lessons are identified. Firstly, retention can be problematic with older people becoming tired (Clarke, et al. 2009; Grönvall & Kyng 2013), finding it hard to focus for long (Duh, et al. 2016) or fully engage particularly for people with cognitive impairment (Span, et al. 2018). To address this, authors suggest the need to be flexible (James, et al. 2015), allow plenty of time (Jacobs, 2010; Nguyen, et al. 2019; Span, et al. 2018; Wang, et al. 2014; Zeitz, et al. 2011), allow time for small talk (Span, et al. 2018) and consider the unique support needs of each person (Jewitt, et al. 2016) including physical, sensory or cognitive impairment (Boerema, et al. 2016). Secondly, communication and trusting, facilitative relationships were considered key (Tanner, 2012). To address this, approaches included the use of artefacts. For example, three representational artefacts: emotion maps, stories, and tracing paper were used by Morrison & Dearden (2013) to help to facilitate interactions between lay participants and health professionals. A web-based research platform offered an opportunity to view study progress as not all participants were able to attend every session (James, et al. 2015). Cue cards were valuable memory prompts and building on people's own experiences and adequate briefing/debriefing in supported full, respectful and meaningful participation (Tanner, 2012). Finally, empowerment, equity and power relations were considered to be necessary both for the process (Baur & Abma, 2012; Jacobs, 2010, Morrison & Dearden, 2013; Wang-Letzkus, et al. 2012) and outcome (Buckley, McCormack & Ryan, 2018; Flinn, et al. 2013). Cultural awareness and language proficiency were

considered necessary (Isaacson, 2018) along with a non-linear, reflexive process with space to exchange ideas and experiences (e.g. Baur & Abma 2012; James, et al. 2015; Morrison & Dearden, 2013). Additionally, more time than expected may be needed and timeframes should be flexible (Wang, et al. 2014). When under time pressure there was a tendency to slip back into more traditional researcher/participant relationships (Jacobs, 2010). The need to get to know participants and understand the local community (Buckley, et al. 2018; Span, et al. 2018; Wang-Letzkus, et al. 2012) and understanding of organisational dynamics (Hewitt, Draper & Ismail, 2013) was considered essential. Tanner (2012) was the only author who noted the importance of maintaining contact with the team during fallow periods of the process.

Discussion

We identified 48 papers reporting on C-MW with older people in health care intervention design, development or delivery research. Our aim to report *how* older people were engaged was met as most papers clearly reported stages of the project and to some extent the practicalities of older person involvement. In summary, older people were rarely engaged in planning or disseminating work. Their contributions were almost entirely concerned with providing data and to a lesser extent data analysis. Older people largely provided information predominantly in interviews, focus group and workshops and in design and development of a range of interventions including training, eHealth, web and hard copy information and equipment. Heterogeneity of intervention was notable indicating a somewhat ad hoc approach to engaging older people in C-MW, seemingly often driven by local enthusiasts rather than being an approach embedded in policy.

Assessment of *how well* older people were engaged in the process proved more challenging.

Variation in C-MW approaches and limited reporting about method and context make it impossible to draw robust conclusions about which approaches are most useful in which circumstances. Many studies were not explicit about the aim of the C-MW per se, and did not evaluate their work from

this perspective. Rather than uncovering papers that illustrate best practice, our review has highlighted gems of good practice which illuminated researcher's commitment to C-MW. These were often small extracts which we were drawn to and which offered a key to understanding what matters. Beyond existing principles (Arnstein, 1969; Aner, 2016, Teoh, et al., 2018) we have identified gems of good practice and from these derived pragmatic recommendations for enhancing future C-MW with older people. Preparation is key, researchers need to consider *why* they are choosing to use C-MW and then articulate this to older people including discussion of expectations and limitations. Time should be taken to build trusting relationships and skilful facilitation is essential to promote empowerment and equitable participation. Retention can be problematic and may be supported by researchers being sensitive to signs of fatigue and disengagement and adjusting activity accordingly. The use of artefacts, such as cue cards, emotion maps and creative activities may support communication in a generation that are perhaps not used to sharing their opinions in such a forum.

There are a number of limitations to our review. It is possible that our search strategy did not identify all studies. We have taken a systematic approach to identifying relevant papers, however the slippery nature of the concept (Schaufeli & Salanova, 2011) of co-methodologies may mean that other reviewers would have included different papers. We are mindful that some included studies are at the borders of PPIE / research participation / consultation but were included as authors categorised them as C-MW. The heterogeneous nature of the interventions described perhaps make comparisons challenging, however we argue that C-MW is more about underpinning philosophy and ways of working rather than the detail of actions, although advancing knowledge in this area through practical examples is helpful.

We selected the Co:Create Co-Production Matrix to guide analysis of *how well* C-MW had been enacted, but this was not unproblematic. We recognise that the Matrix is a self-assessment tool but

selected it as offering the best fit with our area of interest. The Matrix offers eight descriptors at four levels which encompass the complexity and variability of C-M. The Co:Create Team are clear that the Matrix is, and may always be, a work in progress as C-MW evolves (Hewitt, C. personal communication, April 22, 2020). We argue that adherence to too rigid a framework may undermine the principles of C-MW and that the Matrix is best used to enable colleagues to think about which elements are most important for their work and how these may best be achieved.

Judgements about Co:Create scores inevitably have an element of subjectivity and descriptors overlap. There was broad consistency in scores across reviewers, in areas of disagreement we discussed the rationale for decision making in order to seek consensus view. We are mindful that low scores may be attributed to lack of reporting rather than the C-MW being of lesser quality. Thus, as stated elsewhere in this paper we question the value of scoring.

Placing our findings in the context of wider literature, a review of the role of older care-home residents as research advisors or collaborators included 19 papers reporting 11 studies (Backhouse, et al. 2016). Two key themes emerged; variances in residents' engagement and barriers and facilitators to involvement. Whilst identification of barriers and facilitators is valuable, suggestions for addressing these serve to raise more questions, for example, development of trust (how do you do that), researchers willing to share control (what might that look like) and suitable venue (what is that). A systematic review of participatory action research (PAR) in gerontology (Blair & Minkler, 2009) offers an analysis of 13 exemplars reporting 10 studies presented under pre-defined PAR principles. The authors provide grounded suggestions on how effective engagement may be achieved. These include respect for life experiences, building two-way trust, and sufficient preparation. These authors highlight the need to accept that research will produce exemplary rather than generalisable results and the need for personal investment and tolerance of delays. Littlechild,

et al. 2015) suggests the need for broad inclusion to ensure representation of hard to reach groups (e.g. people living with dementia or from the black and minority ethnic communities).

Broad-based reviews of C-MW with other age groups, but still within the context of healthcare are scarce. The exception is an investigation to identify the concept of healthcare co-production and discuss its effects and implications. In contrast to our review, Palumbo (2016) concludes from included papers (n= 65), co-production in healthcare is problematic predominantly due to health care practitioner “hostility” and patient “unwillingness” to engage. If co-production is to improve this author suggests a need for greater inter-disciplinary working, more effective lay-practitioner communication and greater use of information technology. This difference in findings may be attributed, at least in part, to our clinically focused lens as opposed to the management perspective of Palumbo (2016).

In essence, existing research on C-MW with older people in healthcare concurs with our findings. It suggests practitioners and researchers who are committed to, but not always yet highly skilled in the practice of C-MW. Although C-MW with older people is an emerging field it may be that it is more advanced than is recognised given Palumbo’s (2016) findings of hostility and unwillingness to embrace C-MW. These reviews highlight areas for development whilst our review extends knowledge to offer practical directions for future C-MW working with older people in healthcare.

In all areas of research there has been a proliferation of checklists and reporting guidelines. Most closely allied to this review is the GRIPP 2 checklist to report patient and public involvement in research (Staniszewska, et al., 2017). We have no doubt of the value of transparent reporting however, we urge caution against employing checklists as “how to” tools. Checklists can imply rigidity that is counterintuitive to the non-linear and dynamic nature of C-MW. The use of any ladder, wheel or matrix of C-MW potentially implies that all elements are of equal importance and

that to be successful a project should score as highly as possible in each. Notably, despite some high quality examples of C-MW, none of our included papers reached the maximum score. We argue that notions of 'best' and 'scores' are an oxymoron in C-MW and that aiming to achieve highly in all elements may stifle C-MW, particularly in the real world of health care where resources are finite and we may be working with people with varying degrees of functional and cognitive challenges. What is more important is that researchers move towards C-MW where appropriate. We argue that engagement at every stage of a project may be unrealistic in some circumstances as studies may be prolonged and the level of commitment beyond what any individual can offer. So for example, a solution may be to work with different older people for each element, with some overlap for shared understanding. This may reduce the risk of studies simply fading into obscurity once the doing element has been completed. Incremental change is the way forward, small change, not big talk (Hewitt, C. personal communication, April 22, 2020). Slavishly aiming to reach high scores in a particular domain may not be helpful, researchers and practitioners need to do what is right for people and purpose and have time to consider and articulate to *why* they are choosing C-MW and what they hope to achieve. This will inform which elements of any ladder, wheel or matrix are most pertinent to the particular study and therefore what needs to be reported. Measurement using entire frameworks can be antithetical and dispiriting to researchers and practitioners who are working to advance C-MW in health care intervention design, development or delivery. However, we encourage future C-MW with older people to report participants' experiences of the process to enable others to learn about what works for who and in what circumstances.

Our review, in which we have mapped, synthesised, identified gems of good practice and offered pragmatic directions for improving CM-W in healthcare with older people is of value to clinicians, managers and policy makers who are planning such endeavours. This new knowledge will help to inform future co-working and benefit the older population.

Conclusion

Our review demonstrates the diverse use and reporting of C-MW with older people. We found a lack of clarity about whether aims from participation had been met. Establishing *how* older people were engaged in C-M was largely straightforward. *How well* this was done was more challenging, however we have identified gems of good practice. The Co:Create Co-Production Matrix was the best fit for evaluating papers, however it is not intended as a measure per se. In essence, we argue that notions of 'best' and 'scores' are an oxymoron in C-MW, what is important that: i) researchers embrace these methods, ii) incremental change is the way forward, iii) researchers need to do what is right for people and purpose and iv) have time to consider and articulate to *why* they are choosing C-MW and how best this can be achieved for their particular situation. Future evaluation of all participant's experience of the process would enable others to learn about what works for who and in what circumstances.

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Table 1 Key search terms

older or elder* or senior AND co-design or co-production or co-creation or 'participatory research' or 'participatory design'.
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Table 2 Eligibility criteria

Inclusion	Exclusion
<p>Design:</p> <ul style="list-style-type: none"> • Peer-reviewed empirical research of any design • Relevant to health care in its broadest sense (primary care, secondary care, independent sector, community settings), focus on healthcare interventions • Explicit use of co-methodologies (co-design, co-production and co-creation or participatory research, participatory design) <p>Population: Participants older people as defined by the authors (older, elder, senior)</p> <p>Limiters: English language, 2009-2019</p>	<p>Design:</p> <ul style="list-style-type: none"> • Non-peer-reviewed articles, editorials and discursive (opinion) papers, protocols, theses, grey literature • Not healthcare related, for example interventions to improve the environment, housing or circumstances such as social isolation • Focus on engagement, involvement or consultation of service users without specific reference to 'co-' or 'participatory' methodologies <p>Population: People not defined as older by authors</p> <p>Limiters: Non- English language, not 2009-2019</p>

Table 3: Co:Create Co-production Matrix (re-produced with permission of Co:Create)

Descriptor	Not started (0)	Bronze (1)	Sliver (2)	Gold (3)
Holistic: Coproduction should happen at every stage	We're not doing this and we've not started to think about it yet	Coproduction takes place at one stage only e.g.: just at the beginning or at evaluation; predefined by select or organising members of the group	Coproduction takes place at two-three stages that are typically predefined by select or organising members of the group	Coproduction takes place at each stage, including planning, delivery, evaluation and governance of the project
Resourced: Meaningful and effective coproduction deserves and requires sufficient resource	We're not doing this and we've not started to think about it yet	Coproduction is delivered but is given little resource and preparation time. Project timeframes can be inflexible	Sufficient resource is given to some stages of coproduction but not all. Planning and preparation are often given insufficient resource or time	Sufficient resource is given to coproducing at every stage. Resources are committed to the activities and allocation is flexible. Project timescales are adjustable to enable meaningful coproduction
Transparent: Coproduction should have a clear and transparent remit i.e.: overall aims, limitations, expectations and commitment	We're not doing this and we've not started to think about it yet	Participants understand some of why they are involved or the remit of the coproduction activity but there's a lack of transparency	Participants understand why they are involved but the remit is fixed and cannot be challenged	All participants understand why they are involved and the remit of the coproduction. Participants can challenge and reframe as required
Inclusive: Coproduction should involve a wide range of people (e.g.: practitioners, customers, future users, the wider community), capturing individual and differing views	We're not doing this and we've not started to think about it yet	Coproduction activities primarily engage 'usual suspects' and little review of accessibility and reach is carried out	All coproduction activities are designed for accessibility but little extra resource is committed to reaching a wide range of people	All coproduction activities are designed to be as accessible as possible in order to consider all relevant viewpoints. All participants have relevant experience to draw upon. Extra resource is committed to involving a wide range of people
Iterative: Coproduction should be reciprocal, repeated, and progressive, always adapting and building upon what came before	We're not doing this and we've not started to think about it yet	The coproduction process sometimes starts from scratch rather than building on what came before. Some feedback is given to participants but it is not always accessible, clearly recorded or evidenced.	Coproduction begins at an ad-hoc stage in the process (i.e., it does not build on what has come before). Feedback is always given to participants but it is not always accessible, clearly recorded or evidenced	Information circulates through feedback loops enabling all participants to access feedback, challenge or build upon information, and feed back into the information cycle. Individuals give and receive feedback reciprocally. All feedback is accessible, clearly recorded or evidenced
Positive: Coproduction should be mutually beneficial and an overall positive experience	We're not doing this and we've not started to think about it yet.	Participants are heard but there is little evidence that they would get involved again	Participants feel heard and valued but the process is not particularly beneficial to them. Alternatively, participants may believe the process is beneficial, but do not feel that their thoughts are heard or valued	Participation is valued and individuals feel heard. Participants are engaged, committed and empowered. Participants report positive experiences and feel that their time has been well spent. Participant expectations are established and met.
Equal: Each participant and their contribution should be valued equally	We're not doing this and we've not started to think about it yet	Coproduction is accessible to some but not to all possible participants. Some	While coproduction is accessible, some participants feel less valued, important or	All participants of coproduction feel equally valued and heard. Any potential

		aspects of the problems and solutions are identified and resolved collaboratively but not all	knowledgeable than other participants. Problems are identified collaboratively but solutions are not	issues relating to power imbalance have been redressed. Problems and solutions are tackled collaboratively
<i>Sustainable: Meaningful coproduction should have a genuine sustainable impact on the project</i>	We're not doing this and we've not started to think about it yet	The coproduction does not directly relate to the sustainability of the service or project. Only a few participants understand and can articulate the impact coproduction has had	Some participants understand and can articulate the impact of coproduction on the sustainability of the service or project, but this is not clearly recorded or evidenced	The impact of coproduction on the sustainability of the project or service is clearly recorded or evidenced. All participants understand and can articulate the impact that coproduction has had

Table 4 Data extraction from included papers

Authors, year, country	Aim of study	Methodology	Co-approach	Aim of co-approach	Participants	Summary of co-procedures	Total Co:Create score
Allen, Azuero, Csikai, et al. 2016 USA	To recruit, train, and retain Legacy Intervention Family Enactment (LIFE) intervention volunteers.	Process evaluation	Community-based participatory research (CBPR)	To provide insight into how the LIFE project could be improved.	Volunteers (n=45, reducing to 12 trained and 6 worked with a family), researchers.	Volunteers gave feedback at several points during the process.	12
Baur & Abma 2012 The Netherlands	To improve meals in a residential home.	Process evaluation	Co-design	To improve relations and interaction with and among groups in the home.	Female residents (n=7), researcher.	Group discussions and meetings.	19
Boerema, van Velsen, Vollenbroek-Hutten, et al. 2016 The Netherlands	To design mobility aids that address real needs.	Qualitative	Co-creation	To translate end-user knowledge into product innovation.	People (n=10) who need / may need mobility aids, researchers, designers and caregivers.	Interviews with older people and workshops with all.	9
Bond, Mulvenna, Finlay, et al. 2015 UK	Design of a reablement system.	Qualitative	Co-creation	To elicit requirements and test usability of a digital reablement system.	Clinicians, managers, community members, technologists, service users and researchers.	Ideation event, requirement gathering early prototyping, quasi-hackathon, usability study.	17
Bone, Edington, Rosenberg, et al. 2013 USA	To improve cancer screening.	Process evaluation	CBPR	Active engagement and meaningful participation from community stakeholders.	Health staff, academics, community organisations, and cancer survivors (n = unclear).	Recruitment, training and evaluation of community health workers, navigators and supervisory staff.	20
Brocklehurst, Mackay, Goldthorpe, et al. 2015 UK	To enable older people to prioritise the research agenda in improving their oral health.	Qualitative	Priority setting partnership.	To build consensus through steps prioritising research agendas.	Carers (n=6) users (n=11), third sector and specialists, researchers.	Questions in advance. Group discussion. Consensus process.	17
Buckley, McCormack & Ryan 2018 Republic of Ireland	To evaluate the effects of the implementation of a methodological framework for a narrative-based approach to person-centred care in residential care homes.	Qualitative	Participatory Action Research	To elicit requirements and usability of a methodological framework from staff and residents.	Nurses and carers (n=38); Residents (n=37).	Staff = work-based learning groups. Residents = focus groups discussions and interviews.	13
Bulsara, Khong, Hill et al. 2016 Australia	To assess the effectiveness of world café in redesigning a falls prevention resource.	Qualitative	World café, seven integrated principles.	To provide an atmosphere conducive to exploring ideas, thoughts, and beliefs.	Convenience sample of older people (n=73) living at home, researchers.	Facilitated conversations.	18

Authors, year, country	Aim of study	Methodology	Co-approach	Aim of co-approach	Participants	Summary of co-procedures	Total Co:Create score
Clarke, Sanders, Seymour et al. 2009 UK	To evaluate participatory and responsive working in developing and piloting a program with peer educators.	Process evaluation	Action research	To work in participatory and responsive manner.	Academic researchers (n=5), peer educators (n=5), voluntary group representatives (n=3).	Literature review writing a peer education guide. Developing and implementing, testing and evaluating.	17
Duh, Guna, Matevž, et al. 2016 Slovenia	To improve the user experience of telemedicine and telecare solutions.	Qualitative	Participatory design	To involve users in research and design activities.	Older adults (n=45) and researchers.	Researchers compared differences in participatory processes.	10
Ellins & Glasby 2016 UK	To report on hospital and discharge experiences of older people from minority ethnic communities.	Qualitative	Participatory action research	To shape research agenda and co-produce its outcomes.	Older people from minority ethnic communities (n=8), researchers, members of partner organisations.	OP were recruited, trained and then conducted an interview-based study, including data analysis.	20
Flinn, Sanders, Yen, et al. 2013 USA	To explore participation experiences of elderly women with hand limitations in tools for improving bottle openability.	Qualitative (nested in mixed-methods)	Participatory design using make, tell and enact model	To design with end-users and explore participation experiences.	Retirement facility residents (n=26) and researchers.	Making, presenting and explaining model lids.	14
Giesbrecht, Miller, Mitchell, et al. 2014 Canada	To develop a therapist-monitored wheelchair skills home training program delivered via a computer tablet.	Qualitative	Participatory action design	To engage OP wheelchair users, care providers and clinicians in iterative design and development.	Manual wheelchair users (n=10), care providers (n=4), clinicians (n=20), researchers.	Two sets of focus groups (n=8) as part of phased study design identifying issues and discussing prototypes.	15
Giroux, Tremblay, Latulippe, et al. 2019 Canada	To develop an eHealth tool to promote early identification of the needs of carers for functionally dependent older persons	Qualitative	Co-design	To work in partnership with community organisations, health and social care staff and care givers	Caregivers (n=30) Community workers (n=26) Health professionals (n=18)	Sorting method, personas, eHealth tool analysis, brainstorming, sketching, prototyping and pretesting in eight co-design sessions and three advisory committees	17
Godfrey, Smith, Green, et al. 2013 UK	To develop a novel delirium prevention system of care for acute hospitals.	Qualitative	PAR	To facilitate stakeholder learning and consider strategies for implementing a delirium system of care.	Staff, patients, carers, voluntary service managers, volunteers and researchers (n = unclear).	Facilitated workshops. Interviews and focus groups with multiple stakeholders. Observation of ward practices.	10
Goeman, King, Luu, et al. 2016 Australia	To develop a 'talking-book' tool to address low health literacy in Vietnamese OP with dementia.	Qualitative	Co-design and participatory action research.	To select content and language, refine content and evaluate the acceptability and utility of the book.	Members of the Vietnamese community (n=59), multiple stakeholders and research team.	Appraisal of existing information, presentation of content to advisory group.	12

Authors, year, country	Aim of study	Methodology	Co-approach	Aim of co-approach	Participants	Summary of co-procedures	Total Co:Create score
						Community consultation. Focus groups and interviews.	
Grönvall & Kyng 2013 Denmark	Dizziness in OP, reports on participatory element only.	Qualitative	Participatory design.	To understand the needs of physiotherapists and OP in falls clinics and how to develop a home-based technology-assisted intervention.	Physiotherapists (n=2) and patients of the falls clinic with dizziness (n~20), researchers.	Discussion of prototypes.	20
Hales & Fossey 2018 UK	To design a computerised CBT package for carers of people with dementia	Qualitative	Co-production	To address limitations of previous online interventions by including users and experts as consultants and collaborators throughout the project.	Clinical experts professionals (n=8) Academics (n=2) CCBT experts (n=2) Carers by phase: 1. (n = 1) 2. (n = 28) 3. (n = 103)	Three phases 1.data-gathering from literature and semi-structured interviews 2.co-production and Refinement 3.pilot field testing	11
Hewitt, Draper & Ismail 2013 UK	To analyse and improve quality of life in a residential home for older people	Process evaluation	Participatory approach	To involve residents and staff as closely as possible in improving the home	Researcher, residents, staff, committee chairman, administrator, domestic staff, local organisations (n = unclear)	Participant observation Interviews Community engagement, Focus groups Priority setting Voting by residents	13
Holliday, Ward & Fielden 2015 UK	To understand OP views of electronic assisted living technology and explore development of solutions.	Qualitative	Co-creation	To create a shared vision and ownership of ideas and concepts developed.	Consumers (n=18), prospective consumers (n=24), industry representatives (n=13), researchers.	6 co-creation workshops.	12
Hwang, Truong, Cameron, et al. 2015 Canada	To explore how ambient assisted living (AAL) might support or collaborate with informal care partners (ICPs) of people with dementia	Qualitative	Multi-phase co-design process.	None documented	ICPs (n=6) and researchers	4 stage user centred design. Design workshops. Paper prototype tested in people's homes.	12
Isaacson 2018 USA	To explore palliative and hospice care with Native American elders.	Qualitative	Community-based participatory research.	To bring about change within the community by power sharing among all participants (including the researcher).	Native American elders, health professionals and researchers (n=unclear).	Talking circle – similar to a focus group, but this is a culturally-appropriate method of CBPR, where Native Americans share stories specific to the focus area.	13

Authors, year, country	Aim of study	Methodology	Co-approach	Aim of co-approach	Participants	Summary of co-procedures	Total Co:Create score
Jacobs 2010 The Netherlands	To understand healthy living of Dutch and Moroccan OP and develop activities to promote their health and empowerment.	Process evaluation	Community-based participatory action research.	To contribute to empowerment of the community of OP.	OP (n=8), health practitioners (n=2), researchers (n=3) and academic project manager (n=1).	All collected stories from OP in community. Monthly meetings. Sub-groups and researchers met separately from practitioners and community participants.	10
James, Blomberg Liljekvist, et al. 2015 Sweden	To formulate municipality guidelines to address deficiencies in elderly care.	Process evaluation	Participatory and appreciative action and reflection.	To involve stakeholders to create and agree core values and local guarantees of dignity in elderly care.	Participants (n=386), older people, area and unit managers, relatives, nursing assistants, researchers.	Observation, interviews, focus group discussions and critical review face-to-face and virtually.	15
Jewitt, Hope, Milne, et al. 2016 Canada	To develop and evaluate a patient education pamphlet on lung radiotherapy.	Qualitative	Participatory design.	To involve OP at each stage to ensure that the target population's needs and questions are addressed.	Researchers, clinical staff, patients (n=37), patient education specialist and a graphic designer.	Interviews older people, draft written by researcher and presented to interdisciplinary team, revised pamphlet tested with patients.	9
Koops van't Jagt, de Winter, Reijneveld, et al. 2016 The Netherlands and Hungary	To develop a health literacy intervention to support OP when communicating during their primary care consultations.	Qualitative	Co-creation	To ensure that intervention would reflect themes, issues, and strategies that were relevant and authentic to the target group.	Health care professionals, older adults with low health literacy, researchers (n=variable with phase between 3-16).	Literature review, formative evaluation of needs and preferences of target population, role-play, intervention planning and development, pilot testing.	17
Lucero, Sheehan, Yen, et al. 2014 USA	To design web-based falls prevention system for community-dwelling OP.	Qualitative	Consumer-centred participatory design.	To enable users contribute to the design and development of a system across different design specification requirements.	Community-dwelling older adults (n=30 for focus group and 15 for design phase). Researchers.	Four participatory design sessions. 90 minutes.	13
Morrison & Dearden 2013 UK	To enable older patients and staff representatives to work together to drive improvements.	Process evaluation	Participatory design. Theories of boundary objects.	To gain OP's perspectives on attending outpatients' clinic, and facilitating them to take part in designing solutions.	Older patients, staff, carers, researchers and charity workers (n=unclear).	Gathering and sharing older people's emotion maps, facilitated discussions to agree priorities, participatory activities to explore solutions.	20
Nguyen, Bol, van Weert, et al. 2019 The Netherlands	To co-design an existing hospital website with patients and professional stakeholders with the aim to make it more user-friendly for older patients	Qualitative	Multi-phase co-design process.	Using the co-design process in order to offer older patients with cancer a usable website.	Phase 1: Content: Patients (n=11); Physicians (n=3); Researchers (n=8). Design: Patients (n=9). Phase 2: Content: Patients (n=20);	Multimethod approach: insights from existing literature; qualitative (e.g. usability study); quantitative (e.g. experiment); empirical studies conducted by the	16

Authors, year, country	Aim of study	Methodology	Co-approach	Aim of co-approach	Participants	Summary of co-procedures	Total Co:Create score
	with colorectal cancer (CRC).				Physicians (n=5); Nurses (n=1); Researchers (n=5); Other non-health staff (n=2). Design: Patients (n=6); Physicians (n=3); Nurses (n=2); Researchers (n=5); Others (n=2). Phase 3: Design and Content: Patients (n=10); Physicians (n=3); Nurses (n=2); Researchers (n=5); Other (n=1).	project team, and expert knowledge from all relevant stakeholders.	
Parker, Chen, Pillemer, et al. 2012 USA	To adapt an evidence-based Arthritis Self-Help Program (ASHP) for older African American, Hispanic and non-Hispanic white adults.	Qualitative	Method for Planned Adaptation through Community Engagement.	To improve fit, extend reach and effectiveness of ASHP for target group.	Older people, instructors and researchers (n=unclear).	Community steering committee, implementing original program, feedback and adaptation using shared decision-making.	17
Ralston, Young-Clark & Coccia 2017 USA	To reduce cardio-vascular risk in mid-life and older African Americans.	Qualitative	Community-based participatory research.	None documented.	300 older African American church members and researchers.	CSC organised stakeholder advisory groups. Research advisory group completed interactive, iterative processes.	16
Rapaport, Webster, Horsley et al. 2018 UK	To design and test a sleep intervention to improve sleep for people living with dementia	Qualitative	Co-production through meaningful PPI.	To develop an accessible and engaging intervention drawing on the experience of 'experts by training' and 'experts by experience'.	Researchers. Carers of people living with dementia (n=4 / n=5).	Consultation with 'experts by experience' Focus groups at two stages	16
Revenäs, Forsberg, Granström, et al. 2018 Sweden	To co-design an eHealth service for the co-care of Parkinson disease	Process evaluation	Co-design	To co-design an eHealth service for the co-care of Parkinson disease	Researchers People with Parkinson disease (n=7) Health care staff (n=9)	Four x ½ day co-design workshops using Nominal Group Technique and focus groups Evaluation of co-design process by all participants	20
Sadler, Sarre, Tinker, et al. 2016 UK	To develop and evaluate a novel intervention to promote resilience after stroke.	Qualitative	Co-design.	None documented.	Stroke researchers, health professionals and service user representatives (n=unclear).	Existing knowledge discussed with stakeholder panel. Stakeholder panel co-designed intervention.	13
Sandlund, Lindgren, Pohl, et al. 2016	To design and develop a mobile exercise application to prevent falls.	Qualitative	Participatory and appreciative	To understand OP views on falls risk and preferred prevention interventions.	Community-dwelling older persons (n=18) and researchers in physiotherapy, informatics	10 workshops with computer-based materials developed and revisited over a year.	18

Authors, year, country	Aim of study	Methodology	Co-approach	Aim of co-approach	Participants	Summary of co-procedures	Total Co:Create score
Sweden			action and reflection.	To design a mobile application with personal balance and strength exercises.	and knowledge engineering.		
Schensul, Radda, Coman, et al. 2009 USA	To increase resident ability to make informed decisions about influenza vaccination, and to build internal and external infrastructure to support sustainability.	Qualitative	Multi-level peer-led empowerment intervention.	OP to promote vaccination practices in their buildings using a peer-leadership and communications model.	Social scientists, researchers, geriatricians, public health nurses, service providers and resident OP (n= unclear).	Committee trained to merge existing lay and professional knowledge. OP share knowledge in two half day flu events and creation of a flu movie.	21
Siek, Khan, Ross, et al. 2011 USA	To design an e-based intervention to allow OP and their caregivers to manage their own health information.	Qualitative	Participatory design.	To ensure all stakeholders have a voice in the design process.	Older people (n=22) in six user studies, caregivers (n=9), experts in care transitions (n=4), and research team.	User studies with 3-8 participants, think aloud session and review of different iterations of prototypes.	13
Smith-Jackson, Carroll, Kim et al. 2010 USA	To understand OP needs for the Near and Far Environmental Awareness System (NaFEAS) for OP with visual impairment (VI).	Mixed methods	Participatory design.	To design with people with severe visual impairments.	OP with VI (n=5), respondents to questionnaire (n=50) and research team.	Design session with OP with VI Online questionnaire of OP with VI.	8
Span, Hettinga, Groen-van de Ven, et al. 2018 The Netherlands	To understand the participatory design approach of involving people with dementia in the development of an interactive web tool facilitating shared decision-making in their care networks.	Process evaluation	Participatory design.	To facilitate shared decision-making in the care networks of people with dementia, an interactive web tool, the <i>DecideGuide</i> , was developed.	Semi-structured interviews (n=23); Focus group interviews at a day care centre (n=9); Focus group sessions with mock-up (n=12); Usability tests (n=3); Field study (n=4). Researchers.	Participants were consulted at all stages of the development of the interactive web tool.	18
Subramaniam & Woods 2016 UK	To establish an evidence base for using multi-media digital life storybooks with people with dementia in care homes.	Mixed methods	Participatory design.	To create a life story movie fully directed by the person with dementia.	Older people with dementia (n=6), their relatives, care home staff and researchers.	OP designed, created and directed personal life story using "Windows Movie Maker". Researcher was co-editor.	16
Sukwatjane, Pongthavornkamol, Low, et al. 2011	To explore perspectives of OP on impact of taking part in a diabetes self-help group.	Mixed methods	Participatory action research.	To work collaboratively through the stages of PAR in relation to a diabetes self-help group.	Older people (n=20) and research team.	Relationship building. Attendance at 10-12 self-help sessions, reflection and revision in light of feedback.	16

Authors, year, country	Aim of study	Methodology	Co-approach	Aim of co-approach	Participants	Summary of co-procedures	Total Co:Create score
Thailand							
Tanner 2012 UK	To investigate older people's experiences of transitions into and between dementia care services.	Process evaluation	Co-research	To engage older people with dementia (PWD) in the research process.	Co-researchers (older PWD, n=3), interview participants (n=5) and researchers.	OP conducted interviews with academic researcher as a second interviewer.	17
Tremblay, Latulippe, Giguere, et al. 2019 Canada	To identify requirement for an eHealth tool to support help seeking by caregivers of functionally impaired older adults	Qualitative	Co-design based on qualitative action research	To accurately identify needs from the perspectives of all involved	Caregivers (n=11) Community workers (n=10) H&S care staff (n=11)	Four co-design workshops, one advisory committee session	16
van Velsen, Illario, Jansen-Kosterink, et al. 2015 Netherlands and Italy	To develop a community-based, technology-supported health service for detecting and preventing frailty and further functional decline.	Qualitative	Participatory design.	To include all stakeholders including end-users.	Wide range of stakeholders, including older people from the local community.	Large meeting with nine subsequent meetings in each site Development and refinement over time of "ideal service model".	13
Wang, Hardin, , Zhou, et al. 2014 China	To recruit Chinese immigrant older adults to attend chronic disease self-management (CDSM) program and evaluate its applicability.	Qualitative	Practical participatory evaluation (P-PE).	To guide the development and evaluation and to generate even balance of power.	P-PE team of OP (n=5), church leaders (n=2), researchers, CDSM OP (n=18).	P-PE team met weekly x 4, then monthly to monitor progress. Focus groups to evaluate programme.	13
Wang-Letzkus, Washington, Calvillo, et al. 2012 USA	To reflect on collaborative process of developing a nursing intervention for older diabetic Chinese American immigrants.	Process evaluation	Culturally competent CBPR and VPCM (Vulnerable population conceptual model).	To gain insight into the health beliefs, attitudes, and practices of selected communities.	OP, staff at day care centres, and researchers.	None documented.	19
Yankeelov, Faul, D'Ambrosio, et al. 2015 USA	Initial community engagement activity to promote trust-building, part of larger comprehensive community needs assessment.	Qualitative	Photovoice, community-based participatory action methodology.	Engage at individual, interpersonal and community levels. Link needs assessment to community participation. Promote critical dialogue.	Older people with diabetes (n=23), community organizers and researchers.	OP photos and narrated everyday personal lives. Selected six to share in half-day focus group session with posters. At least one 2-hour community event.	15

Authors, year, country	Aim of study	Methodology	Co-approach	Aim of co-approach	Participants	Summary of co-procedures	Total Co:Create score
Zeitz, Kitson, Gibb, et al. 2011 Australia	To identify issues experienced by OP acute care that could be improved through a collaborative approach to action.	Process evaluation	Co-operative inquiry.	To facilitate the dialogue between older people and clinicians.	OP (n=4), clinicians (n=4), facilitators (n=3), researchers.	Five workshops over four months with reflection at end and circulation of notes and agreed actions.	15